



Via electronic mail

Dec. 8, 2010

Secretary S. Kimberly Belshe
California Health and Human Services Agency
1600 Ninth Street, Room 460
Sacramento, CA 95814

Mr. William Barcellona
Co-Chair, California Privacy and Security Advisory Board
c/o California Association of Physician Groups
1215 K Street, Suite 1915
Sacramento, CA 95814

Ms. Pamela Dixon
Co-Chair, California Privacy and Security Advisory Board
c/o World Privacy Forum
2033 San Elijo Avenue, No. 402
Cardiff by the Sea, CA 92007

RE: CalPSAB's Advisory Board's vote on October 12, 2010 concerning consent policy

Dear Secretary Belshe, Mr. Barcellona, and Ms. Dixon:

I am writing to support CalPSAP's Oct. 12, 2010 vote requiring opt-in consent before an individual's data is shared beyond the immediate treatment circle through electronic HIE. Frankly, I thought this was a settled matter and am disturbed by efforts to overturn the decision.

HIE is just getting established. It is imperative that during a start-up the health system retains consumers' trust. Opt-in does just that. The choice does not limit an individual's ability to get healthcare treatment; it simply requires that permission be given before a patient's data is shared with other entities outside the treatment circle.

Studies have shown that when patients have doubts about the security of their health records, they are reluctant to seek necessary treatment for sensitive health conditions. California has a strong interest in encouraging individuals to seek prompt treatment for serious health conditions, including those that may have a stigma attached to them such as HIV-AIDS, substance abuse, mental health, sexual assault, domestic violence, and even genetically-linked diseases. If people fear the sensitive information may not be in their control, they may delay treatment or avoid it altogether. We want to avoid this outcome for Californians, and for HIE.

The World Privacy Forum believes that the middle ground for California is to take a transitional approach to HIE. Consumer Watchdog endorses that course. We see that technology will ultimately enable sequestration of sensitive information. When this occurs, opt-out with opt-in for sensitive data will make much more sense. But until then, opt-in across the board is the least risky and safest approach. It is the method that will foster necessary consumer trust.

In its groundbreaking report on online privacy last week, the Federal Trade Commission took the position that medical information should require an opt-in approach.

Consumer Watchdog appreciates the thoughtful efforts that state has undertaken to determine a pathway forward in HIE policy. We believe the Oct. 12 vote endorsing opt-in was the culmination of that process. Our greatest concern is that the consumers of California achieve the maximum benefit HIE has to offer while being protected from the risks such a system by its nature introduces. These risks can be mitigated by a thoughtful opt-in approach at this point in time. Consumer Watchdog urges you to stay with the opt-in approach.

Sincerely,

A handwritten signature in black ink, appearing to read "John M. Simpson". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

John M. Simpson
Consumer Advocate

Cc: Alex Kam, Jonah Frohlich, Joe Munso